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ABSTRACT

Although little emphasis has been placed on the community-based long-term care needs of the black elderly, examination of the needs of this group is important because of the projected rapid growth and the overall poverty rate of this population. Because personal care homes may be the only option currently available for the black elderly when traditional family networks change, a study was conducted to identify the needs and characteristics of caregivers and their black elderly clients in community-based personal care homes. Trained volunteers collected data from both caregivers (N=153) and carereceivers (N=184) through interviews in the respondents' homes in five urban and four rural sites. Carereceivers ranged in age from 49 years to 104 years; the median age was 76 years. Most were very poor and viewed themselves as frail and in poor health. Many caregivers reported income below the poverty level with their only source of income being caregiving. Over 60% were single, the median caregiver age was 55 years. As the age of the carereceiver increases, demands for care will likely increase. Yet the results of the study suggest that their caregivers are also approaching or are in the older age groups. Personal care home living arrangement may be suitable in the short term, but may not be desirable as time progresses because of the increasing needs of both caregivers and carereceivers. (Eight policy options are recommended based on results of the study.) (NB)

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Caregivers and their black elderly clients

American Red Cross

CG 020796

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Caregivers and their black elderly clients

Caregivers and Their Black Elderly Clients *is the executive summary of* Characteristics and Needs of Black Caregivers and Their Elderly Clients in Personal Care Homes, *which was prepared by the American Red Cross under a grant from the Administration on Aging, Office of Human Development Services, Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy. The policy recommendations are those of the investigators and not necessarily those of the American Red Cross.*

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Finally, 90 volunteers participated in this study, and it is to their efforts and to the caregivers and carereceivers that this study is dedicated.

EXECUTIVE SUMMARY

Introduction

The American Red Cross and the Congress of National Black Churches are pleased to present this report on the findings from a study funded by the Administration on Aging designed to identify the needs and characteristics of caregivers and their black elderly clients in community-based personal care homes. This study provides information that will assist nonprofit organizations, churches, community groups, and government agencies to identify ways to strengthen caregivers' support of the black elderly in these personal care arrangements and to provide insights for future research.

The study's findings are important because so little emphasis has been placed on research focused on the community-based long-term care needs of the black elderly beyond studies of family members as caregivers and of nursing home populations. Examination of the needs of the black elderly is particularly important in view of the projected rapid growth of this population (a projected increase of 45.6 percent between 1980 and 2000) and because of the overall poverty rate (32 percent for black elderly and 57 percent for older black women living alone). Further examination of the community-based needs of the black elderly is even more important because personal care homes may be the only option currently available for the black elderly when traditional family networks change, such as when young blacks migrate out of rural communities leaving little or no family networks behind, and when family networks break down or do not exist.

The major research questions under study were—

- What are the characteristics of individuals receiving care in these homes?
- What are the characteristics of individuals serving as caregivers in personal care homes in the black community?
- What services are being provided to older blacks by caregivers in these homes?
- What support services are being provided to caregivers and by whom?
- What do caregivers need to improve the quality of their services?

This study was carried out from January 1986 to May 1987. Trained volunteers collected data from both caregivers and carereceivers through face-to-face interviews in the respondents' homes. The data collection instruments that were constructed specially for this study were designed for standard administration. They were based on widely used data collection instruments in the aging field. Interviews were conducted in five urban sites (Atlanta, Ga.; Baltimore, Md.; Cleveland, Ohio; Detroit, Mich.; and Oakland, Calif.); and four rural sites (counties in Alabama, Mississippi, North Carolina, and South Carolina). A total of 153 caregivers and 184 carereceivers were interviewed, 62 percent from rural areas and 39 percent from urban areas. Further information on the study design and limitations is appended to this summary.

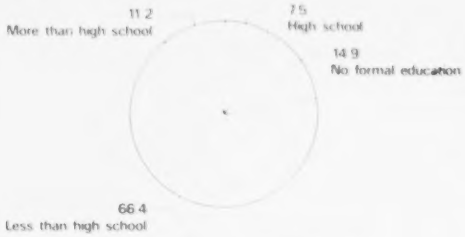
Characteristics of Carereceivers

Carereceivers ranged in age from 49 to 104; the median age was 76 years. Those over 75 years comprised 57 percent. Only 15 percent were married; the rest were single; most were widowed (55%).

Marital Status

Most of the carereceivers in the sample were widowed. About 30 percent were either divorced, separated, or had never married.

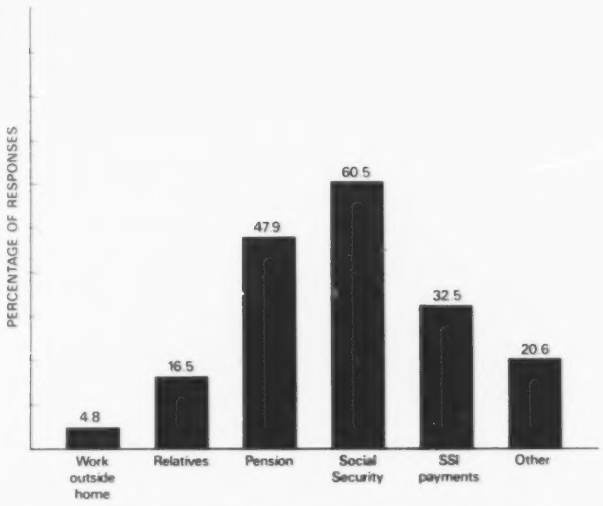
Education



Most of the sample had less than a high school education. Of the remaining, over one half had completed high school or more. The rest had no formal education.

The carereceivers in this sample were very poor. For those who reported an income, the range was 0 to $763 per month; the median monthly income reported was $58.00. Social Security was the most frequently reported source of income (60.5%), followed by pension (47.9%), and Supplemental Security Income (SSI) payments (32.5%). Most (35%) reported no source of income, one third had two sources, and 27 percent had one source. Some of the income data may not reflect carereceivers' sources of income from federal and state funds because some social service agencies paid the caregivers directly. Nevertheless, the data strongly suggest that some carereceivers were eligible for, but were not receiving SSI payments. Outreach and information about SSI and help in enrolling in this program may ensure that those who are eligible can receive the benefits they are entitled to by federal law. Furthermore, some could also be eligible for the state's Medicaid program.

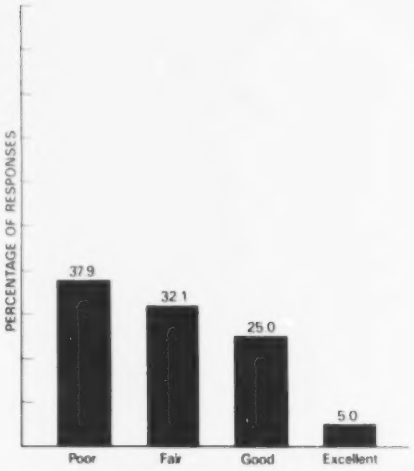
CARERECEIVERS' SOURCES OF INCOME



About 92 percent of carereceivers in the sample reported a monthly income of less than $400.

Reports by carereceivers about their health "now" (at the time of the interview) and changes in their health (now versus in the past) suggested that they viewed themselves as a particularly frail group. Thirty-eight percent reported their health as poor, followed by fair (32%). Many (43%) reported poorer health than when they first arrived at the current place of residence. Most, however, reported that their health was better (32%) or the same (24%) since they had come to the home.

CARERECEIVERS' REPORTS OF THEIR HEALTH STATUS



Most of the carereceivers reported their health at the time of the interview as poor or fair. Forty three percent reported their health as poorer than when they first moved to their present place of residence.

Caregivers were more likely to report their carereceivers' health as fair or good. In comparing the current health of the carereceivers to their health when they came to the home, the caregiver was more likely to report the carereceivers' health as better (41%), or the same (39%), and few (17%) reported carereceivers' health as worse.

The most frequently reported illnesses or health conditions for carereceivers were diabetes (42%), high blood pressure (33%), arthritis and angina (each 30%), cancer (29%), and anemia (27%). The most frequently reported equipment/devices used by carereceivers were: glasses/contact lenses (69%), dentures (52%), a walker (39%), a cane (34%), bedside commode (26%), and a functioning wheelchair (24%).

A measure for identifying unmet needs was achieved by asking the carereceivers what help or additional help they needed in their daily activities. Of the six activities of daily living (ADL) reported, most carereceivers reported that they needed help with bathing (26%), followed by help in getting in or out of a bed or chair (16%), dressing (13%), eating (4%), and toileting (3%). Less than 19 percent reported that they had bladder and bowel accidents, yet caregivers reported this as the third most frequent ADL where assistance was provided. Of the seven instrumental activities of daily living (IADL), most respondents reported that they needed help with housework (31%), followed by meal preparation (27%),

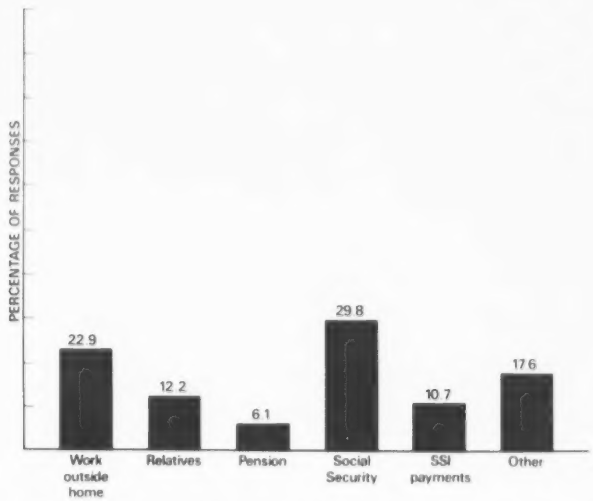
transportation (26%), grocery shopping (23%), telephone use (20%), and money management (9%).

When asked what kind of help was needed, the carereceivers had modest requests, such as grab bars to help with getting in and out of a tub and rides to church.

Characteristics of Caregivers in Personal Care Homes

The portrait of the caregivers in this study sample suggests a vulnerable group. Many reported income below the poverty level (69.5%) with their only source of income, for the most part, from caregiving (70%). Over 60 percent were single and of these nearly one half were widowed. Their ages ranged from 15 to 87 years, with a median age of 55 years.

CAREGIVERS' SOURCES OF INCOME

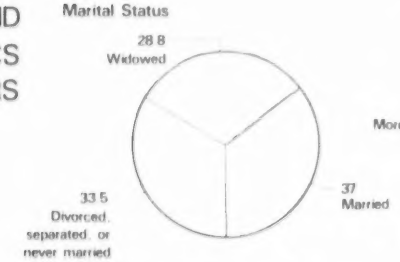


Over two thirds of the caregivers reported income under $400 per month. Seventy percent reported that caregiving was their only source of income.

Their education varied widely, ranging from no formal education to college completion. The majority (52%) had at least a high school education.

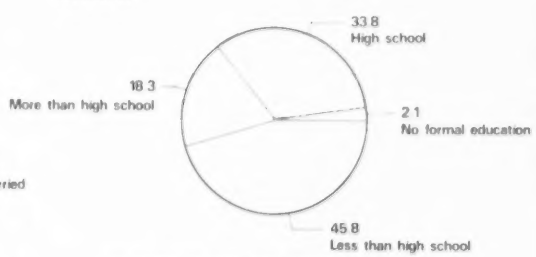
BACKGROUND CHARACTERISTICS OF CAREGIVERS

Marital Status



More than one third were married, some were widowed, and one third were divorced, separated, or never married.

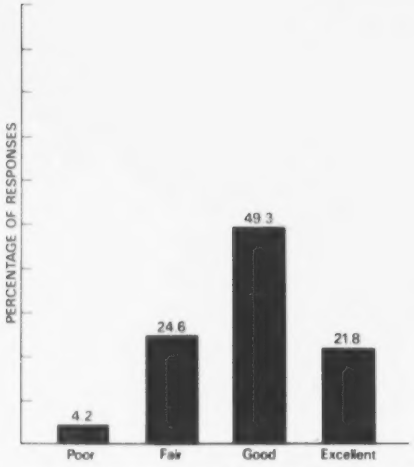
Education



The majority of caregivers in the sample had some high school education or had completed high school. Almost one fifth had more than a high school education.

Slightly over one quarter (29%) reported their health as fair or poor; the rest reported their health as good (49%) or excellent (22%). The majority reported few health conditions and illnesses, the most frequently reported were high blood pressure (46%), arthritis (44%), or anemia (18%). The life satisfaction data suggested that their sense of well-being was positive.

CAREGIVERS' REPORTS OF THEIR HEALTH STATUS



The majority of caregivers reported their health as good or excellent, with less than 5 percent reporting good health. Over three quarters also reported that their health was the same compared to a year before they were interviewed.

These data suggest that aging persons in the community are at least finding a source of employment and satisfaction in caregiving but that they could also be facing, in the not too distant future, the need for their own community-based care. Because of the reported low income, some caregivers might be eligible for federally funded programs such as SSI. In addition, they themselves might benefit from programs directed at maintaining or improving their health such as a health promotion course for older people.

Services Provided

The majority (55.7%) of caregivers reported that they had been giving care to older people for more than five years. Most gave care to only one person (45%) or two people (20%). Many caregivers reported that they get some time off from caregiving. Most attend church at least one time per month (78%) and less than one half get time off from caregiving sometime during the week. However, when asked if they had a regular schedule away from caregiving, almost one half indicated that they did not; and the majority felt the need to escape from caregiving sometimes or often. This need is understandable in light of the caregiving activities performed. These data suggest that an area in need of attention in the aging field may be providing relief for the non-family caregiver.

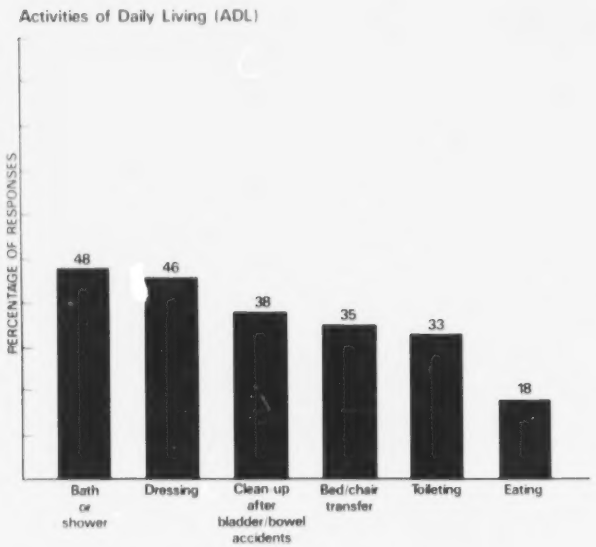
Both the caregivers and carereceivers report a wide range of activities and services provided by caregivers. Most caregivers

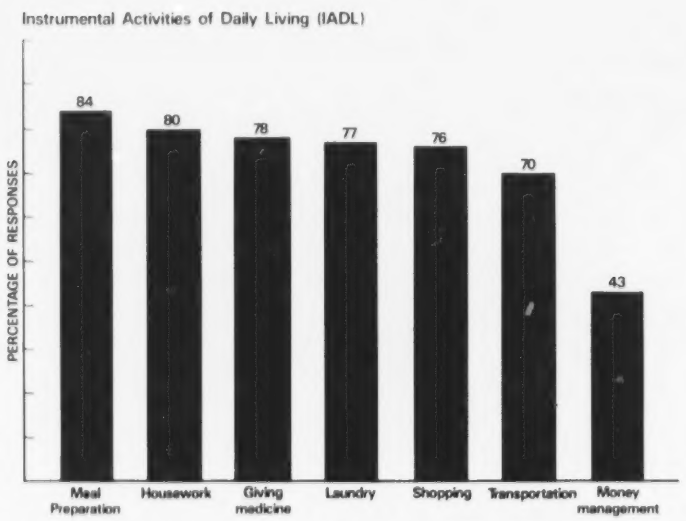
help with IADL but fewer provide help with ADL. They also helped with medications, indoor and outdoor mobility, and such things as sewing clothes or "anything that is needed."

The following summarizes the type of help caregivers report in relation to IADL and ADL activities. The most frequently reported activities are listed first:

IADL		ADL	
Meal preparation	84%	Help with bath or shower	48%
Housework	80%	Help with dressing	46%
Giving medicines	78%	Help clean up bladder or bowel accidents	38%
Laundry	77%	Help in/out bed or chair	35%
Shopping	76%	Help with toileting	33%
Transportation	70%	Help with eating	18%
Money management	43%		

SERVICES PROVIDED BY THE CAREGIVERS





Caregivers provided assistance to carereceivers for the full range of ADL and IADL. About 84 percent of the caregivers provided assistance for one or more of the IADL, while less than one half reported providing assistance with any of the ADL.

12

In addition, 24 percent gave medical treatments in the home, including oral medications, injections, oxygen, changing bandages, and I.V. medications. When asked whether or not they felt they needed help in performing duties, most said they did not. Of those who said they needed help with IADL activities, they ranked transportation first (19%), followed by help with housework (18%) and meal preparation (15%). Twenty-one percent said they needed help with personal care activities (ADL).

Importantly, many caregivers had received some type of training related to caring for someone at home, such as basic training in first aid (57%), taking vital signs (56%), home nursing (53%), and CPR (50%). However, nearly two thirds (63%) had not received any courses on aging or care for the elderly, few (24%) had received stress management training, and only 22 percent had training in money management. Many reported that they would like additional training (62%) in such courses as CPR, care of the elderly, home nursing, and first aid.

The data suggest that training programs should be designed with the caregivers' education and experience in mind. Because the majority have had several years of caregiving experience, the training programs should consider experiential learning as the method of choice, thereby drawing upon the opinions and experience of the group. Furthermore, individual learning approaches should be attempted, such as demonstration in the home of a particular procedure, activity, or method. The data also suggest that course content and individual consultation should include the latest methods and technologies for bladder and bowel control and best practices in providing ADL and IADL assistance. Some caregivers, because of the relatively low level of education and the possibly lower level of literacy, may need programs designed especially to meet these needs.

To take advantage of training programs and other supportive activities, caregivers may need relief from their responsibilities in the home for several hours over a period of time.

Support Services to Caregivers

Support of family caregivers is an area of concern to which current attention and resources are being directed. Non-family members are no less deserving of this attention. When caregivers were asked if they received help, few (28%) reported help with ADL from family, other relatives, or agencies. The most help they received was with activities related to IADL: transportation (45%), meal preparation (33%), and shopping (29%). Few caregivers perceived a need for help or more help with ADL (21%); a significantly greater number perceived a need for help with IADL (49%); yet, many said they would like additional training. Caregivers should be encouraged through individual or group training to identify what help they need and how to make the agency receptive to this need.

Caregivers were also asked about services provided by others that they found to be most useful. These services in order of frequency were: health and social services provided by local agencies, help in and around the home, in-service training, transportation, and financial support.

Respite services are needed that would permit the caregivers time off from caregiving to widen their own social experience and to participate in the training that they feel would strengthen their ability to care for the elderly.

Summary

In summary, these data contribute important information about a segment of the aging network that is too often overlooked or forgotten—non-family caregivers. Programs to assist these caregivers and their elderly clients should address the nature of long-term care in personal care home settings and consider the demands for health and social and supportive services for both caregivers and carereceivers. As the age of the carereceiver increases, one can anticipate that their demands for care will also increase, and, if their health deteriorates, increasing demands for more complex care are likely. Yet their caregivers, just as family caregivers, are also approaching or are in the older age groups.

This situation requires the attention of policy makers. Personal care home living arrangements may be suitable in the short term but may not be desirable as time progresses because of the increasing needs of both caregivers and carereceivers. Other less restrictive care arrangements will need to be considered and made available. In addition, because of the multiple needs of many carereceivers and caregivers, case management by nursing and social services should strongly be considered for this population.

Much can be done. Some tasks are more easily accomplished than others, such as donating and installing assistive devices to make care easier for the caregiver and more comfortable for the carereceiver. Programs such as the Interfaith Coalition on Aging have demonstrated that volunteers from churches and organizations can provide substantial help with these types of activities and that this population would benefit from similiar assistance in their communities. Other activities require policy considerations, such as making a variety of housing options available, particularly in rural communities. Other policy considerations also include expansion of Medicare benefits to address the long-term care needs of in-home services. Of particular importance to the emergency care network are the disaster preparedness planning efforts that must take into consideration the needs of caregivers and the people to whom they give care in community-based care arrangements. Together, the public and private sectors of this country can work to improve the quality of life for the most senior members of society, particularly those in greatest need. This study is but one small effort to make this possible.

Policy Options and Recommendations to the Administration on Aging

The following policy options are recommended to the Administration on Aging based on the findings of this study.

1. Provide funding for continued training, education, and on-site demonstration for caregivers in personal care homes.

The availability of training increases the quality of care available to the carereceivers. Furthermore, increasing the skills, ability, and self-reliance of caregivers may increase their levels of life satisfaction.

2. Support funding of programs that provide case managers and nursing consultation for caregivers and carereceivers in personal care homes.

Both caregivers and carereceivers in this study found services from the formal health (primarily nursing) and social service systems to be the most helpful of the available resources. As carereceivers get older, their demands and needs for care will increase. Meanwhile, the age of the caregivers will also be increasing, affecting caregiver needs, especially assistance with caregiving. Expert nursing consultation for carereceivers, development of care plans, and 24-hour consultation would benefit both caregiver and carereceiver.

3. Support legislation that expands the home care benefits available under Medicare to include non-medically based services for non-homebound individuals with chronic conditions.

There was a need among the black elderly in this study for home health care and services rendered outside of institutions. There was also need indicated for services that offer support and assistance to the caregiver such as adult day care. The availability of the funding would strengthen the ability of elders to remain self-sufficient.

4. Support and intensify social and health service planning, particularly in the southeastern states and other rural areas, and provide needs clarification to suppliers of transportation and other services.

The respondents in this study indicated a need for assistance in transportation and related services. Many more caregivers and carereceivers would be able to attend church, social activities, and other opportunities if transportation, especially for the frail or handicapped elderly individuals, is readily available.

5. Support respite care services for caregivers of elderly.

The majority of caregivers indicated that they sometimes feel a need to escape from the caregiving site. In addition the caregivers need to be able to leave the home for shopping, banking, and other duties for themselves and the carereceiver. Available quality respite care will provide that opportunity for

the caregivers to leave the home knowing that the carereceiver is well cared for. In addition, caregivers will be able to attend training sessions to upgrade their skills. Respite care provides carereceivers with care, companionship, and stimulation from a committed individual other than the regular primary caregiver.

6. **Increase efforts to disseminate information about the needs of older black women, using media, especially TV campaigns and public service announcements.**

This approach may encourage the elderly and their caregivers to seek out information on aging services. The research data from this study indicated that the majority of personal care home caregivers and carereceivers is composed of black females. The data also indicated some lack of knowledge or desire for additional knowledge about federal and local programs for the elderly.

7. **Provide funding for research comparing various elderly populations (male/female, minority/majority, urban/rural, etc.). Studies should explore problems that keep black and other elderly from participating fully in programs for the elderly.**

There is a void in the current literature about caregiving arrangements for the black elderly outside of immediate family and institutional settings. Through research more information would be available for use in developing policies and programs to serve various elderly groups more adequately.

8. **Provide funding to support greater research emphasis on the attitudes of various groups, especially black, poor, and rural elderly regarding alternative housing and health care arrangements.**

There is currently a dearth of literature on the attitudes of elderly toward specific health care arrangements and housing options. Research data may guide future policy and planning regarding use of services and programs.

SURVEY DESIGN AND DATA LIMITATIONS

Survey Design

The American Red Cross, in cooperation with the Congress of National Black Churches, conducted face-to-face interviews with 153 caregivers and 184 carereceivers in personal care homes from June 1986 through March 1987. The sample was drawn from five urban sites (Baltimore, Atlanta, Cleveland, Oakland, and Detroit) and four rural sites (counties in Mississippi, Alabama, North Carolina, and South Carolina).

Both urban and rural sites with a strong proportion of older blacks in the community were selected. Rural communities were included in the design because of the continuing evidence that a significant proportion of older blacks reside in rural American communities. In 1982, 17.4 percent of blacks over the age of 65 were living in rural areas, especially in isolated rural areas.

Criteria used to define, identify, and screen personal care homes for inclusion in the study were: (1) a private residence or home small enough to create a family-like environment; (2) no more than six elderly persons are receiving care; (3) at least one carereceiver was a black elderly person (the age of the target carereceiver was not specified, but it was expected that they would be age 55 or older); (4) the caregiver is not an immediate family member of the carereceiver (i.e., caregiver could not be the mother/father, brother/sister, husband/wife, or daughter/son of carereceiver); and (5) the caregiver provides room and board as well as activities, such as supervision, assistance with activities of daily living, administration of medicines or treatment, and patient advocacy. Homes could be licensed or unlicensed. Personal care homes were identified primarily by using a "snowball" sampling technique. This sampling technique involved listing those personal-care homes that research team members in the field had compiled from available sources and that fit the study criteria. These homes were then contacted and asked to identify other homes that also fit the criteria. This process was repeated until duplications started appearing on the list. (See Sudman, S. *Applied Sampling*, New York: Academic Press, 1976.)

Volunteer interviewers were included in the design because previous experience by the Red Cross demonstrated that volunteers, properly trained and supervised, are capable of reliably collecting data. However, it was also recognized that the use of volunteer interviewers can create problems of interviewer reliability. To forestall these problems, interviewers received intensive training. Topics in the training program included: obtaining consent, methods of conducting an interview and recording data, types of problems encountered during interviews and solutions to these problems, obligations of the interviewer to the respondent, and possible demands of respondents on researchers.

Because of the geographic distribution of sites and the involvement of volunteers, the research design included a

number of procedures to gain valid and reliable data. These procedures included:

- Selecting data-gathering instruments based on wellknown and widely used instruments in the aging literature: The National Long-Term Channeling Demonstration, the National Survey of Black Americans, the Life Satisfaction Index-A, and the Mental Status Questionnaire. Separate instruments were developed for caregivers and carereceivers.
- Consulting an expert advisory panel regarding data-gathering instruments and overall research design.
- Selecting sites based on the 1980 census to identify urban and rural sites with a high proportion of blacks in the elderly population.
- Specifying criteria and procedures for personal care home identification.
- Implementing snowball sampling techniques.
- Determining selection criteria for and training of interviewer trainers.
- Determining selection criteria for and training of volunteer interviewers.
- Implementing procedures for site coordination and support and supervision of interviewers.

The research team that was assembled included project staff at Red Cross national headquarters as well as field staff in each site. The field staff included: (1) a site coordinator, responsible for overall coordination of activities; (2) a field interview trainer, who trained and monitored volunteer interviewers; (3) 10 to 12 volunteer interviewers at each site who conducted the interviews; and (4) a church liaison to coordinate activities with local churches. All procedures, including identification of personal care homes, training of interviewers and evaluation of the instruments, were tested in a pilot study. The findings from the pilot study were incorporated into the final research design, development of the instruments, and the training of field interview trainers and interviewers.

Limitations of the data

The nature and design of this study dictate the reasonable assertion that there are factors inherent in the project that may limit the ability to generalize or to interpret the data.

There is limited information on the documented numbers of black elderly currently residing in personal care homes. Thus, it is not possible to state the degree to which the sample is representative of the overall population in these community-based living arrangements. The data are limited to caregivers who consented to be involved, honored the agreed-upon interview appointment, and completed a lengthy interview. Those caregivers who refused to make an appointment for an interview, or those who did not complete the interview because of an inadequate Mental Status Questionnaire (MSQ) score, or terminated the interview prematurely, are not included in the

sample. A possible result of this selection process could be that the data are limited to respondents in the better caregiving arrangements.

Also, some carereceivers were not able to be interviewed because they did not score high enough on the MSQ screen or were too physically ill. Thus, the carereceiver data, while providing a portrait of a vulnerable group, may paint a more positive picture than would actually be revealed if we had collected information on all carereceivers regardless of their physical health and functional ability (e.g., through a respondent other than the caregiver who was very familiar with the carereceiver's condition).

There are limited data on the applicability of the Mental Status Questionnaire and the Life Satisfaction Index-A for use with minority populations. Although widely used in the aging field, these instruments were validated and tested for reliability on a predominantly white middle-class population. Data are scarce on their appropriateness for use with black populations. Therefore, though these are standard measures, caution should be exercised in interpreting these data.

Some demographic and service delivery data were not provided for some questions. Missing data may have been due to the personal nature of some questions (income, age, etc.); or to response bias (tendency to give socially acceptable responses, e.g., related to care provided or received), or no answer at all.

EXPERT ADVISORY PANEL TO THE BLACK ELDERLY CAREGIVERS' STUDY

Patricia Archbold, D.N.Sc., R.N., F.A.A.N.
Professor
School of Nursing
Oregon Health Sciences Center

Claudia Baquet, Ph.D.
Director, Minority Field Program
National Institutes of Health
National Cancer Institute

Beverly A. Baldwin, Ph.D., R.N.
Assistant Professor
School of Nursing
University of Maryland

Marie J. Bourgeois, R.N., Ph.D.
Graduate Faculty
School of Nursing
Georgetown University

Marjorie Cantor, Ph.D.
President
Third Age Center
Fordham University

Frank Cherry, Ph.D.
Independent Consultant

Gene Gary-Williams, Ph.D.
Associate Dean
College of Allied Health
Howard University

Rose Gibson, Ph.D.
School of Social Work
University of Michigan

Mary Harper, Ph.D.
National Institute of Mental Health
Mental Disorders of the Aging Research Branch

John Hatch, M.S.W., Ed.D.
Professor, Health Education
Department of Health Education
School of Public Health
University of North Carolina

Donna Lind, Ph.D.
Associate Professor
Department of Health Services Administration
George Washington University

John McAdoo, Ph.D.
University of Maryland
School of Social Work

Julianne Oktay, Ph.D.
Associate Professor
School of Social Work and Community Planning
University of Maryland

Joan L. Quinn, M.S.N., R.N.
President
Connecticut Community Care, Inc.

Laura Reif, Ph.D., R.N.
Associate Professor
Family Health Care Nursing
University of California

Susan Sherman, Ph.D.
School of Social Welfare
Rockefeller College of Public Affairs and Policy
State University of New York at Albany

Delois Skipwith, R.N., D.S.N.
Chairman, Level III
School of Nursing
University of Alabama

Barbara Soniat, ACSW, LCSW
Assistant Professor
Gerontology Program
George Washington University Medical Center

Barbara J. Stewart, Ph.D.
Professor
School of Nursing
Office of Research, Development and Utilization
The Oregon Health Sciences University

Wilbur Watson, Ph.D.
Center on Aging
Atlanta University